



# Thalassemia

## WHAT IS THE PUBLIC HEALTH ISSUE?

Thalassemia is a group of genetic blood disorders that affect approximately 1,000 individuals in the United States. People with thalassemia have a genetic defect of their red blood cells that affects the cells' ability to produce normal hemoglobin. Red blood cells use hemoglobin to carry oxygen to tissues. As a result of the defect, most forms of thalassemia produce a chronic, lifelong anemia that begins in early childhood and often must be treated with frequent transfusions. Significant, often life-threatening complications are common in the most severe forms.

## WHAT HAS CDC ACCOMPLISHED?

Developed a new program and awarding funds to:

- Establish a standard approach to diagnose and provide care for persons with thalassemia.
- Support outreach and education activities aimed at encouraging health behaviors to prevent complications of thalassemia.

## WHAT ARE THE NEXT STEPS?

- Establish the National Data Collection Project, which is a system to monitor persons with thalassemia for bloodborne pathogens to ensure blood safety.
- Establish a network of specialized health-care centers to promote the management, treatment, and prevention of complications experience by persons with thalassemia.
- Establish outreach initiatives to identify under-served patients and promote relationships between their local health-care providers and the specialized health-care centers to coordinate and deliver management, treatment, and prevention services for persons with thalassemia.
- Encourage collaboration between the specialized health-care network and community-based organizations to enhance outreach and education.